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Platinum Opinion

Response to the Council of Europe Human Rights Commissioner's Issue Paper on Human Rights and Intersex People

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In May 2015, the Council of Europe (COE), represented by its Commissioner for Human Rights, published an issue paper on human rights and intersex people.

While we appreciate that the paper aims to increase public understanding of how children and adults live with these conditions and are cared for, and is concerned with the fundamental human rights related to this community, we feel that it is flawed in the following respect. First, we question the authority of the Lesbian, Gay, Bisexual, and Trans (LGBT) movement to speak on behalf of this community and their families. Second, we feel that views from important stakeholders such as support and advocacy groups and associated health care professionals are underrepresented, and we do not think the ideas outlined are those of the mainstream in the affected community. Third, current medical practice is misunderstood. Fourth, some of us think the term *intersex people* is not widely recognised as appropriate among adults and children having atypical sex development.

1. Authority of the LGBT movement to represent the community of people with variant sex development

We share the concerns of intersex activists regarding the discomfort of society towards gender variances, but while we recognize the powerful campaigning voice of LGBT groups, we have serious concerns about their involvement in representing people with variant sex development. No such organisations have approached support or advocacy groups about adding "I" to the acronym, as in the LGBTI that is sometimes quoted, and we have no record of LGBT groups in Europe working together with clinical services in optimising care, or of any parental support services having been put in place by them. Grants allocated to LGBT groups to manage "intersex issues" cannot be justified as good use of taxpayer money without consulting such representative stakeholders. Rather, we would argue that the adoption of intersex issues by LGBT under the umbrella of human rights, with the assumption that intersex is per se related to sexual

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[1] European Cooperation in Science and Technology (COST) Action BM1303 is "DSDnet: A Systematic Elucidation of Differences of Sex Development".

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orientation and gender dysphoria or confusion, has a detrimental effect on societal understanding of variances in sex development and undermines the efforts of many people working towards optimal outcomes.

2. Views from the affected community

Intersex activists have often been very effective campaigners, but it is less clear whether they are embedded in and fully represent the community of ordinary people living with variant sex development and their families.

We think it is important to distinguish between the activist voices driving the COE paper and the many community groups who have, from the beginning, taken a support and advocacy approach and have successfully fulfilled a conciliatory role. Their views have greatly influenced medical thinking about care and about how to communicate the issues at stake, challenging both medical and wider social understandings around sex and gender, and questioning the decision-making processes and medical necessity of some forms of treatments and interventions. While many of the concerns raised in the COE paper are recognised and shared by such advocacy and support groups, these groups offer a different perspective on what is needed to address these concerns. Yet they are not given a voice in the COE paper. Why is that?

3. Current medical practice

While the COE paper notes serious concerns about past medical practice, some of which unfortunately persist, it does not recognise what has changed nor what is now widely understood as best practice in the field (Supplementary content). Current medical practice aims to offer a holistic approach and to bring various disciplines together, including the voice of parents and families [1,2]. It (pro-)actively engages with family and support groups to answer their needs effectively, and puts major efforts in reconceptualising care for individuals with variant sex development to limit interventions, offering alternative perspectives at the same time [3,4]. The ultimate goal of such an approach is to optimise outcome while guaranteeing access to specialised health care when needed and building a trustful relationship between affected individuals, their families, and the medical professionals caring for them [5].

What the paper calls "current medical approaches" is to a large extent inconsistent with recently published data and current medical practice [6]. Health care experts and advocates share frustration at the slow implementation of principles agreed on in the 2006 consensus statement and since. However, by not recognising the ongoing evolution in medical thinking thoughtfully and in collaboration with advocates and support groups and by overlooking the positive changes that have been made regarding disclosure [7], gender assignment [8], prenatal dexamethasone treatment [9], and approaches to vaginal hypoplasia [10], the COE paper seems outdated and risks an impression that sensationalises rather than illuminates these conditions. Indeed, we are concerned about the impact on ordinary families and people living with these conditions who may read the paper and withdraw from (medical or psychological) care and/or social interactions, and we urge the COE to reflect on this.

4. The term *intersex*

We understand that some adults reject the medicalisation of variant sex development and the word *disorder*. By the same token, some of us would argue that the majority of medical professionals, and many patients and parents, consider the term *intersex* inappropriate and feel that it increases a sense of stigma around individuals living with these conditions, rather than addressing them. The terms *differences of sex development* and *variances of sex development* are sometimes used to refer to the conditions as a group, although in practice families and affected individuals tend to use the specific name for their condition or that of their child, and few would refer to themselves or their child as "intersex".

In conclusion, we argue that the COE paper misunderstands and thus may misrepresent both current standards of care and the views of the affected community. We urgently suggest that the COE strengthens the legitimacy of the paper by consulting more widely with other stakeholders, including recognised centres of expertise for differences of sex development, overarching structures such as the developing European Reference Network, and established patient representative groups.

Conflicts of interest: The authors have nothing to disclose.

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Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at http://dx.doi.org/10.1016/j.eururo.2016.05.015.

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